



“I can’t make a choice if I’m not well informed”: Ontarians’ advice for improving provincial screening program materials

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Background: *Emerging evidence*

- Our understanding of mammography screening and its impact on overall mortality is changing as new evidence emerges
- Screening has not been found to reduce mortality rates as anticipated. Some lives will be saved, but how many?
- Risks of screening are becoming more apparent, although there is controversy surrounding their magnitude
 - False negatives
 - False positives
 - Unnecessary biopsies
 - Overdiagnosis and overtreatment

Background: *Citizens' perspectives*

- Mammography screening is a “preference-sensitive” decision – there is no clear ‘right’ or ‘wrong’ answer based on the evidence.
- Clinical practice guidelines focusing on the importance of choice
- Recent work in Australia & the UK to gain insights into citizens’ perspectives, but little work in Canada

CMAJ

GUIDELINES

Recommendations on screening for breast cancer in average-risk women aged 40–74 years

The Canadian Task Force on Preventive Health Care

See related commentary by Gøtzsche on page 1957 and at www.cmaj.ca/lookup/doi/10.1503/cmaj.111721



Of the newly diagnosed cases of breast cancer in Canada, 80% were in women

disease (defined as those with no previous breast cancer, no history of breast cancer in a first-

Competing interests:
Marcello Tonelli, Michel
Ioffee, James Dickinson

The Project: *Objectives*

- Elicit citizen values about breast cancer screening;
- Explore policy options to support citizens in making an informed choice regarding mammography; and,
- Compare different strategies for engaging citizens to inform future work in this area.

The Project: *Citizen panels*

- Four citizen deliberations convened between March 2015 – April 2016
 - Panel A: Pan-Ontario, men and women 18+
 - Panel B: Thunder Bay, women of screening age
 - Panel C: Brantford, high screening rates, women of screening age
 - Panel D: Toronto, low screening rates, women of screening age
- Variety of recruitment strategies used including Kijiji, newspaper ads, AskingCanadians survey panel, population survey and re-contacting previous participants
- 48 individuals participated

The Project: *Structure & process*

- Deliberations lasted 1.5 days (Panels A, C & D) or 0.5 day (Panel B)
- Pre-circulated reading material and discussion questions
- Presentation by experts on the emerging evidence on breast cancer screening and it's role in primary care (live or pre-recorded) with Q & A following presentation
- Structured, facilitated deliberation in large and small groups

**Your health;
informed choice**



Join us for a public talk on breast cancer screening: making sense of the evidence

Dr. Jonathan Sussman,

associate professor of oncology, Michael G. DeGroote School of Medicine, McMaster University; associate director, Supportive Cancer Care Research Unit and radiation oncologist, Juravinski Cancer Centre



Wednesday, March 25 7 to 8:30 p.m.

Location | McMaster Innovation Park

175 Longwood Rd. South, Hamilton, Ontario, L8P 0A1

Free admission and parking

Live streamed on the web at

www.anowevent.com/mcmasterhealthforum

One of a series of public talks on health issues

More information at <http://bit.ly/oaevents>

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The Project: *Discussion questions*

- Citizens deliberated on four questions:
 - What citizen and patient values should be reflected in breast cancer screening programs?
 - What principles should guide the development of materials to support informed decision making about breast cancer screening?
 - What should be included in government-sponsored materials about breast cancer screening?
 - How should information about the risks and benefits of breast cancer screening be presented?

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Small Group Activity: *Program materials*

- Small group activity focused on reviewing and reflecting on breast screening program materials
- Materials collected from all Canadian breast screening programs
 - no materials available from Prince Edward Island or New Brunswick
- All small groups reviewed:
 - OBSP invitation letter
 - OBSP brochure
 - 3 – 4 brochures from other provinces
- Each province's brochure was reviewed 2 or 3 times

Key findings: *Participants were uninformed and want more information*

- Most participants had made a choice about screening, but many felt they did not have the information they needed to make an informed choice
- Information about the risks was shocking to participants
- Participants wanted more information when making decisions, but acknowledged having this information could make it harder to know what to do

"I think the decision does become more difficult [with this additional information], but for me that's my decision to make. It's not someone else's decision. It's my decision based on more information. And at the end of the day, I'm the only one responsible for my own health"
(Panel D)

Key findings: *Principles to guide material development...*

- Accuracy
 - Information presented to women through screening program materials should be accurate and honest
 - Example: may not be the best way to protect your health

- Transparency
 - Share everything that is known, not just the information that puts screening in a positive light

The best way to protect your health is by **getting a mammogram every two years**. A mammogram takes an X-ray picture of the breast and can find breast changes when they are too small to feel or see. **You**

Key findings: *Principles to guide material development...*

■ Accessibility

- Information must be easy to read (font size, writing level) and follow (descriptive headings, Q & A approach)
- Information should be easily accessible – sent to women multiple ways (invitation letter, health card renewal forms, in public places such as drug stores, spas, rec centres)
- Begin educating prior to age 50 so women are ready to make an informed decision

Deciding whether or not to have screening mammograms

What are screening mammograms?

A type of screening done to detect signs of breast cancer in women who are healthy. Mammography, the examination method used for this screening, involves x-raying the breasts to look for the presence of cancer.

What happens after the screening mammogram?

A radiologist will analyze your results, at which point two outcomes are possible:

1. The radiologist does not detect any abnormality. This means that no sign of cancer was detected in your breasts at the time of the screening mammogram. However, you should know that it is possible for cancer to be present, but not visible, at the time of a

Key findings: *Principles to guide material development...*

- Support informed choice
 - Information materials must support informed choice
 - Taglines
 - Headings
 - Content
 - Should not assume women will make the decision to be screened



PROGRAMME
QUÉBÉCOIS
DE DÉPISTAGE
DU CANCER
DU SEIN

*Taking part in the
QUÉBEC
BREAST
CANCER
SCREENING
PROGRAM:
It's Your Decision*

How often should I be screened?

- It is recommended that most women 50 to 74 years of age have a screening mammogram every 2 years.
- Some women are invited annually based on family history or the recommendation of the radiologist.

Should I have a screening mammogram?

If you are 50 to 74 and have no breast problems that you know of: have screening mammograms regularly. Research shows that regular screening mammograms can reduce deaths from breast cancer for women 50 to 74.

Key findings: *Principles to guide material development*

- Diversity
 - Materials should be culturally appropriate and represent the diversity present in the population
 - Using graphics and drawings instead of images of people may make this easier.
 - Good examples of this: the bra on the cover of the Ontario brochure; photos of mammography locations, screening vans; drawings



Key findings: *How should risk and benefit information be presented?*

- **Balanced, accurate information**
 - Information about the risks must be included, even when there is uncertainty
- **Multiple levels of information**
 - Basic information for those who do not want the details, more detailed statistics for those who want that level of detail

Effects of screening on...	1,000 participants over 20 years	1,000 non-participants over 20 years
...the number of additional tests	495	325
...the number of breast cancers detected	77	54
...the number of deaths due to breast cancer	13	20
...the number of cases of overdiagnosis*	10	0

Stated another way, the group of 1,000 women ages 50 to 69 who received screening every 2 years over a 20 year period had:

- 170 more additional tests administered
- 23 more cancers discovered
- 7 fewer deaths
- 10 cancers found and treated needlessly (overdiagnosis)*

Written materials are just one source of information...

- Written materials are critical, as not all women have access to health care providers...
- However, in an ideal situation, participants want to be able to learn about the risks and benefits of screening from written materials and from their health care provider

"I would love to walk into a Doctor's office be handed the brochure that gives me the statistical information, the reasons for and reasons against, and then had a discussion with the Doctor about if I'll have a mammogram....I would have felt that I had that strength of knowledge to make the decision on my own" (Panel A)

Future directions: *Pan-Canadian Approach*

- Participants were frustrated to see the variation in the information presented to women across the country
- Women should receive the same, high-quality information regardless of where they live
- Add province specific inserts as needed

"When I go to a McDonalds or Tim's, I want my coffee to be the same right across Canada. So when I go for a medical treatment, and it is more important to me than my coffee, then you know I want to be able to get the same information if I live in Ontario or my child goes to the east coast for school and stays there, I want to know she's getting the same care as I am" (Panel C)

Conclusions

- Women want to be informed about the risks and benefits of screening before making decisions, but this is not happening at the moment
- Current information materials are insufficient and the lack of transparency about the potential harms can erode trust in screening organizations
- A pan-Canadian approach would be preferred by many; consider future partnerships to move towards this goal